Electronic Encyclopaedia of Perinatal Data (EEPD)
Volume I. Discussion Documents
Section W. Whistleblowing Attempts

I. W02. The NHS Maternity Care Data Project:

"Why am I now so disillusioned?" and "What can now easily be done to rescue the project?"

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by
Rupert Fawdry, FRCS (Ed), FRCOG.
Consultant Specialist in Maternity Care, Gynaecology and Medical Information Technology
General Editor: Electronic Encyclopaedia of Perinatal Data (EEPD) Web site: www.fawdry.info
31, St.Mary's Way, Leighton Buzzard, LU7 2RX, United Kingdom
Home: 01525 37 01 37 Fax: 01525 38 24 53 Mobile: 077 68 97 44 13
e-mail: eepd@fawdry.demon.co.uk

or
Contactable c/o The Perinatal Institute, Crystal Court,
Aston Cross (off Rocky Lane), Birmingham B6 5RQ
Tel: 0121 687 3400. www.perinatal.nhs.uk

Any Comments, Criticisms, Corrections or Suggestions for Improvement very welcome

A. Changing Personnel

The project seems to have been originally set up by a civil servant called Eddie Byrne (based in Leeds?) He subsequently left the NHS IT department to continue to work as a civil servant in the Pensions and Benefits department. He was replaced by Steve Chick who I never met. Mr Chick has more recently left the NHS IT department also to continue to work as a civil servant in the Pensions and Benefits department. He was replaced recently by Maurice Ward, who mainly works from home in Stratford on Avon but who is officially based in Winchester. He seems to be involved in many other projects and has more or less inherited this one on the top of his already heavy workload.

The original Project Manager was Andrew Hartshorn who has his own offices in Litchfield. Due to the re-organisation of NHS IT his independent contract was not renewed in March of this year and he has been replaced by an in-house Project Manager called Martin Old, who is based in Taunton.

Project Support was originally provided by Jeremy Orr in the NHS Executive building in Leeds but he recently successfully applied for another post. He has now been replaced as project support by Anthea Plowman in Winchester who only works part time and seems to have other duties as well (Tel: 01962-844588).

Of the original team there remains myself (who was appointed as an obstetrician Clinical Advisor), Jeanette Gilby (a midwife who was appointed with me as Clinical Advisor and who is based in Derby) and four people called “Analysts”, one of whom is based in Stoke on Trent, one is based in Newcastle upon Tyne and a third based somewhere else. (a fourth one seems to have became so disillusioned with the project that he did not renew his contract when it finished at the end of March)

In all SIX core people have now left the project! Is it any wonder it has almost collapsed.

B. Inadequate Outputs

At present I am not even sure where any work so far done is stored, **all I know is that in more than a year I have yet to see anything useful come out of all the work and money spent so far!**

I have attended various working groups which were basically a waste of everyone’s time and I have received by e-mail a) several useless documents based on the expensive working groups and which provide some data modelling and business model information which does not seem to be of any value to anyone,cetainly not to commercial computer companies and b) two Access databases via the E-mail (one which is said to contain a jumble of over 7000 maternity related data items and the other a database list of contacts with an interest in maternity data also jumbled up and with multiple repetitions)

The information in the two databases is of no use to anyone while still in database format and both need to be converted to wordprocessor format for them to be useful. If they were to be converted to a wordprocessor format they might still be useful since expert advisors could then see what they contained and what was missing. In wordprocessor format the relationships would also immediately be obvious such that it would be easy for expert advisors to check if all the right contact organisations had been included and if all the members of all relevant working parties had been documented.

With regard to the maternity data database if this were also to be converted back to a wordprocessor format it would avoid wasting time on definitions without context e.g. the dictionary definition of what is meant by Language! In the context of an electronic record the question is “Are there communication difficulties: Yes/No” if Yes “What fluency does the expectant mother have in English. Reasonable/Poor/None” If “Poor” or “None” then there needs to be a pick list of locally required languages, for which an interpreter might be available. Such information would be of use to health care planners regarding the need for interpreters and to the assessment of the differing workload of different maternity hospitals. How does it help the project to have someone spend time looking up the dictionary definition of ”Language”? There are numerous other examples of the inadequacy of the current database format. This is mainly because in a database it is impossible to see at a glance the kind of relationships which would be obvious in a word-processed document.

That is why all such similar datasets from doctors e.g. the obstetric anaesthetists national data set and the perinatologists national dataset are both distributed in the form of a word-processed document.

C. Wrongly defined “Main Aims” of the project

As most of you are aware I have fairly forceable expressed my views on this ever since the aims of the project first became documented in the February 99 flier (entitled “Maternity Care Data Project. Overview” issued by Andrew Hartshorn, the then Project Manager, dated February 1999 - IMG-reference no.C3237.)

My previous objections are illustrated by the enclosed document which I first circulated in 18th April 1999. (See enclosed blue sheet) In my list as set out there, under the heading “ESSENTIAL PRIORITIES IF THE NHS EXEC MATERNITY CARE DATA PROJECT IS TO SUCCEED” I put as the 6th task. “Setting up a DATA BASE on all known questions, and answers and who might make use of the data” and added “The last objective might be considered to be the first task but will quickly turn out ot be such a massive undertaking that if it continues to be the primary objective it will rapidly overwhelm all other work!!”

From our recent conversations it seems that I was quite right, and as a result although the project has now been running for well over a year, and although a great deal of tax-payers money has already been spent, **nothing useful to anyone has yet been created**!

Using my work

As far as I understand from our recent contacts you are now prepared to ask me if you can use the work I have done independently over the past year in order to try to bail the project out.

I would not have minded this particularly if I was convinced that the project was truly back on track BUT I AM NOT, hence this discussion document.

General Aim

I have no problem at all with the excellent general AIM of the project i.e. that by April 2003, we should have "standardised and consistent recording of data relating to maternity and childbirth which could be captured through Electronic Patient Record systems in all affected NHS organisations to enable and improve: Patient understanding and involvement in their care, seamless care planning, integrated care delivery, clinical governance, service commissioning and development. "

That is, so long as this refers only to "data . . . which could be (realistically) captured through Electronic Patient Record systems." In other words a large (700 questions or so) but limited subset of data which it would be practical to record on every Maternity Electronic Patient Record system.

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Specific Objectives

My problems start with the next section headed "The specific objectives of the project are to:"

1. **Identify, define and standardise the data items to be recorded in the clinical record.**

I. ON THE ESSENTIAL NEED TO TAKE ACCOUNT OF PAPER AS WELL AS ELECTRONIC RECORDS

What is meant by "the clinical record"?

A. AN ELECTRONIC PAPERLESS SYSTEM

If by "the clinical record" one means "the future electronic record", then this is fantasy of the highest order. Maternity care is far too complex and too diffusely practised for any hope of a paperless system for many years. As has been clearly found out in practice with all hospital clinical experience with real patients in real hospitals, it is neither practical nor desirable to totally replace the paper record with a purely electronic system. Even if in time it does prove practical or desirable (which I sincerely doubt) it will certainly not happen within the timescale or financial constraints under which this project can operate.

B. NO UNIVERSAL NATIONAL PAPER RECORD FOR MANY YEARS TO COME

If one modifies this to mean that the aim of the project is "to Identify, define and standardise the data items to be recorded in the paper record (as well as in a complementary electronic record.)", then this is also a matter of fantasy. It has proved to be an immensely uphill task to try to persuade individual consultants, midwives and hospitals to make use of a standard National Maternity Record (so far only about 40 hospitals out of 200) and there seems no likelihood that complete national standardisation of any paper record will be achieved during the lifetime of the National Maternity Care data project.

C. IN ANY CASE STANDARDISATION IS IMPOSSIBLE USING PAPER RECORDS

Even if it were practical to persuade health professionals to use a paper record which contained a minimum degree of conformity, it would still be impossible to standardise more than a minimum of the material contained therein. If such paper records are not to become too bulky to be practical then extensive use has to be made of free handwritten text even for such vital information as to what kind of diabetes a particular patient has or what drugs they are taking. As can easily be seen from checking the work so far done as part of the National Pregnancy Record Project, any detailed standardisation cannot be printed in the record but rather would have to depend on all health care staff being constantly aware of the correct definitions set out in explanatory material.

But paper maternity records are used and written in by virtually every midwife, obstetrician and general practitioner in this country. Is it really practical to believe that they can all be persuaded to enter data as free text in a totally standardised fashion. Impossible!

D. STANDARDISATION OF A NATIONAL MATERNITY ELECTRONIC PATIENT RECORD (EPR)

We now start to talk of something a little more realistic. It is possible and practical to design flow patterned questionnaire based computer systems which force the standardisations of all questions, answer options and help key explanations. They already exist in one way or another in about half of the maternity hospitals in this country.

The problem lies with the practicality and cost-effectiveness of introducing such technology into district based maternity care outside hospital clinics and wards. It will not happen for many years. During any realistic timescale for this project, maternity patients will have care provided in many places where standardised PC computer terminals with appropriate and constantly reliable maternity software will not and cannot exist. Portable computers are costly, need frequent and

expensive hardware and software updating and support, and are far too easily stolen from community based midwives. PDA technology while cheaper are still expensive and are not yet sufficiently standardised. Extending such technology outside hospital and health centre premises will not be cost effective for many years and is therefore impractical as a realistic early aim for this project.

E. A REALISTIC MATERNITY CARE DATA PROJECT

The only place where it might be possible to achieve NATIONAL ELECTRONIC STANDARDISATION AT A REASONABLE COST AND WITHIN A REASONABLE TIMEFRAME is in the LABOUR WARD AND THE POST-NATAL WARDS. Appropriate computer systems are already in daily use in many hospitals. It has already proved practical in many districts for data regarding all home births to be entered on such systems and there is no reason why the aim the maternity care project should not be that standardised data for every birth in Britain should be entered onto a maternity computer system at birth. Suitable computer systems, locally funded, already exist in about half the maternity hospitals. All that is needed are some national standards for a significant part of the data already being collected.

In the light of the above the specific first objective for the project should be changed to:

1. **To identify, define and standardise the data items to be recorded in the <u>Electronic Patient Record at Birth and at the time of Post-Natal Discharge</u>**

   i.e. A NATIONAL STANDARD ELECTRONIC DATA SET - Phase 1 (Labour Ward and Post-natal only)

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II. NEED TO TAKE FULL NOTE OF EXISTING DATA SETS

The second specific objective was

2. **Identify the statistical subsets of data items.**

I have not yet seen any evidence from the material so far sent to me of any useful outcomes under this heading although it seems that some work may have been done.

In the light of the more limited objective suggested above this should now move towards something based on the following:

2A. To identify all existing maternity datasets
50 such data sets have been identified by me so far.
(I don't know what "statistical subsets of data items" means)

2B To take full account of the definitions and answer options of all such datasets in the creations of a unified single National Standard Electronic Data Set - Phase 1

2C To take full account but not be dominated by any relevant definitions in OPCS, ICD-10 and the NHS data dictionary

2D` To document which parts of all existing data sets will be covered by the Phase 1 proposals.

2E To circulate the draft proposals for a National Standard Electronic Data Set - Phase 1 (Labour Ward and Post Natal Wards) to all interested parties including all relevant commercial maternity computer system suppliers

Most of the work required for 2A, 2B and 2D has already been done independently by me. Only a small amount of work remains to be completed on 2C before 2E can be initiated.

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III. SPECIFYING EPR REQUIREMENTS

The third specific objective was

3. **Specify the functional and data requirements for EPR systems to support maternity care**

I have yet to see any useful work done by the project under this heading. I have, however, myself personally and quite separately become involved in a research project entitled "The use of electronic patient records in the maternity services: Professional and public acceptability" It has recently been confirmed that this project has received a grant of £215,000. In my preparation for the grant application I created a short 10 page discussion document entitled "Using Electronic Maternity Records for Patient Care" which could potentially provide the basis for work on this aspect of the project. (But see below for proposed future scope of the project)

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IV. NATIONAL IMPLEMENTATION

The other specific objectives was

4. **Quantify the costs, benefits and impact of national implementation**

5. **Manage a national implementation to be completed by the target date**

I have yet to see any useful work done by the project under these two headings.

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D. OBSOLETE TIMETABLE

The original timetable was as follows.

Stage 1 - Planning and Initiation (Dec 98 - May 99)
Stage 2 - Design and Development (June 99 - Nov 99)
Stage 3 - Piloting and system specification
(Dec 99 - June 00)
Stage 4 - Implementation
(Was due to commence in July 00 and to be completed by Mar 03)

This has been revised once but even the revised timetable now seems to set impossible goals and clearly needs total revision since now, at the end of May 2000, the work of the project has no-where near reached the

end of Stage 2. Surprisingly, if my proposed revision of the specific objectives are accepted, I see no reason why it should not still be possible to aim for full implementation, at least of Phase 1, by March 2003 or even earlier.

E. Poor Organisational Support

How anyone can expect to run a project without proper office support is beyond belief, even in our electronic age. Until recently support was divided between Jeremy Orr in Leeds (whom I personally visited in Leeds and who did not even have access to a reliable reasonable quality photocopier !; but who was almost always available on his office phone since he worked full time) and Andrew Hartshorn's own office in Litchfield.

When I tried with difficulty to contact the new Project Support I was hampered by the fact that the list of addresses and phone numbers she had circulated had omitted her own address and phone number and when I tried to phone her at 11.30 am on a Tuesday I was told that she was part time and had gone home!

When I asked recently no-one even seemed sure where any of the work so far done was actually stored.

It is just not enough to have such material only available on unreliable e-mails however trendy this might seem.

F. Disorganised Finance

This aspect of the project also now seems to have fallen apart. Originally the independent Project Manager seemed to control a reasonable budget from which claims could be made. One of the reasons for the wide interest in this project when it started is that it seemed to suggest that central government finance would in later stages be made available for the universal installation nationally of suitable maternity computer systems.

No such clearly earmarked budget now seems to be available either now or in the future

G. NHS-IT Gobbledegook

On the second page of the flier referred to above there is a long passage which is headed "In general, the approach to developing the maternity Care data is as follows:" It has 5 sections the first of which contains such impractical fantasies as the following "Health Care modelling - understanding, at conceptual and physical levels, what care processes may occur and how they are structured, individually and linked. The project will cover all aspects of maternity and childbirth, spanning organisational and professional boundaries." The other 4 sections are hardly any better.

Such NHS IT gobbledegook and idiocy was virtually guaranteed to destroy any IT project (as it has done)

Until such stupidity is removed from the NHS Information Authority, millions of pounds of tax-payers money will continue to be spent to no avail whatsoever. Through the MUMMIES project and now through the current project; through my 20 year involvement in maternity computing and my 10 year involvement in the continuing success of the PROTOS electronic patient record computer system, I have, as an intelligent and very experienced clinician and as a member of Mensa, been involved in numerous working parties, study groups and other NHS IT work without having ever seen any useful benefit whatsoever from this approach. It may be something that works in industrial factory computing e.g the water boards or the design of post office computer systems but is almost entirely irrelevant to the totally different needs of health care computing in the NHS. Such data care modelling assumes an ability to standardise and control the use of data in a manner which is totally impossible in health care, where virtually every health care professional is in practice almost autonomous in their individual work.

It is so sad to see that after years of such nonsense coming from the Birmingham IT departments, it still appears in such documents as this, and sadly still seems to dominate and cripple far too much of the work of the NHS Information Authority.

If the project is to succeed - and with a total re-think, it can.

If the Maternity Care Data project is to do anything useful the overall AIM as set out above can stay as it is with the proviso that it only refers to potential electronic data.

The specific objectives must, however, be officially altered at the highest level to the following:

A. PREPARATION

A1. Full Awareness of the capabilities of the latest versions of existing maternity computer systems

All those who intend to be involved in the future of this project need to make themselves fully aware of the current design and capabilities of leading edge working maternity computer systems by visiting sites which use the latest versions of at least two of the three main successful maternity computer systems. (Euroking, SMIS/St.Mary's and Protos)

A2. Find out from the existing successsful suppliers of functioning maternity computer systems/ electronic patient records what the NHS IA can most usefully do and not do to improve their service to their many customers.

More than 70 commercial maternity computer systems, mainly from three companies, have now beensuccessfully installed without any help at all from the NHS IA or it's predecesors. If the project is to make any sense it should take careful note of their achievements and not try to re-invent the wheel.

B. CREATION

B1. Identify all existing maternity datasets

50 such data sets have been identified so far, and these have almost all been collected by me in a set of computer files which when printed is now about 150 pages long.

A simple two page list of such known datasets needs to be circulated widely so that any missing datasets can be identified.

B2. To identify, define and standardise the data items to be recorded in the <u>Electronic Patient Record at Birth and at the time of Post-Natal Discharge</u>

i.e. A NATIONAL STANDARD ELECTRONIC DATA SET - Phase 1

This has already been done in a set of 4 documents. Not only does this set out proposals for items to be included in the standard dataset but also documents how much work will be required and by whom to enter data on a computer regarding what proportion of expectant mothers. A set of acceptable answer options is included. Also fully documented is the uses for which it may be required for individual care and who currently finds a need for such data to be collected for later analysis.

This work needs to be completed and then checked before being widely circulated, either in it's full form (about 150 pages) or for most purposes as a simple 20 page list of the data items which it is proposed should be included.

B3 To take full account of the definitions and answer options of all such datasets in the creation of the unified single National Standard Electronic Data Set - Phase 1

B4 To take full account of all existing coding and NHS data dictionary definitions but at no time to be dominated by such definitions. (See also below "What must not be part of the project")

B5 For each existing data set, which items are and are not covered by the Phase 1 proposals needs to be documented.

Proposed Timetable:
There is no reason why with the right simple resources (as set out below) this should not be completed by the end of July 2000 since almost all of this section has already been done independently by myself.

C. CONSULTATION

C1 To create a word-processed list of all relevant organisations, working parties and individuals based initially on those organisations and working parties who have created the so far identified maternity related datasets.

C2 To create a word-processed document which will provide sticky address labels for all of the above contacts.

C3 To circulate the proposals for a National Standard Electronic Data Set - Phase 1 in wordprocessor format to all interested parties, including the commercial maternity computer companies, for their comments.

Proposed Timetable. To be completed by the end of Sept 2000. Not an impossible target since these objectives need to be based mainly on the work I have already done, supplemented by work done in the existing project.

D. PILOTING

<u>At no cost to central government,</u> existing maternity computer companies to be asked to do the following,

D1. to be asked to incorporate the ability to collect all the data proposed in the National Standard Electronic Data Set - Phase 1 data set

D2. to provide in CSV or ACCESS database format any subsets of National Standard Electronic Data Set - Phase 1 as may be required by any interested and authorised party.; with of without individual identification as appropriate.

D3 to pilot such an ability on as many of their existing sites as possible

Proposed Timetable.
To be completed by the end of Dec 2000

FURTHER COMMENT ON THE COST OF PILOTING AND NATIONAL IMPLEMENTATION

When the government decreed that all clocks should conform to Greenwich mean time, it did not consider it necessary to pay for all clocks to be altered. No more should this project be expected to pay for the universal implementation of the proposed NATIONAL STANDARD DATA SET - Phase 1. It should be up to individual maternity computer companies to modify their systems to conform with the national standard data set, and for hospitals only purchase or renew contracts for those maternity computer systems which comply with the proposed national standards.

E. NATIONAL IMPLEMENTATION OF PHASE 1, AND PLANNING FOR FUTURE PHASES

E1 Quantify the costs, benefits and impact of national implementation of Phase 1 for all births in Britain, using hardware supplied by individual hospitals and trusts (which will by then include the hardware and software already provided nationally as part of the NHS number at birth project.)

Proposed Timetable.
To be completed by the end of Dec 2000

Since a large number of maternity hospitals have already managed to find the money to install sophisticated maternity computer systems at their own local expense (as an essential tool in the work of their maternity departments especially in the light of risk reduction requirements) it should not be necessary for central government to provide more than minimal funding for this aim to be fulfilled.

E2. Manage a national implementation of Phase 1 to be completed by the target date

Proposed Timetable.
To be completed by the end of Dec 2001?

E3 In the light of the experience gained in the above, to define, consult about and pilot future phases of the Standard Maternity Electronic Record (e.g. Initial Assessment, Ultrasound systems, etc as set out in the "Captivating Data - Maternity" documentation.)

Proposed Timetable.
To be completed by the end of July 2001

WHAT MUST NOT BE PART OF THE RE-DEFINED PROJECT IF IT IS TO SUCCEED.

1. It must NOT be part of the project to specify the functional and (detailed) data requirements for EPR systems to support maternity care.

This is something for the commercial suppliers to decide, not for government employees. Governments should only do for the people what the people cannot do for themselves i.e. they should define the data outputs required, not how computer systems should be designed and created. Even a small company like Protos has by now had to earn enough income to be constantly creative in this field for 10 years and now to support 17 full time employees and still expanding. There is no justification for Government departments to attempt to compete. or to attempt the impossible task of dominating the commercial world.

2. NO more time and resources from this project to be spent on Data Modelling or Business Activity Modelling of any kind.

Over the past 10 years, despite repeated requests, I have not yet seen any value whatsoever from any work done by NHS IT specialists on data modelling or business activity modelling. Since this project has the potential to be extremely successful without any such work it should not be part of this project to waste it's time on such a futile activity.

If others wish to spend their lives data modelling then there is no reason why they should not use the material from this project after its completion.

3. NO coding as part of the project

While the project will need to take full account of any definitions in the NHS data dictionary and in Read and other coding systems, it must not be part of the project to waste resources on coding and grouping etc. This would be attempting the impossible.

After clinicians (obstetricians, GPs and midwives) have worked out what information should form part of the Standard National Maternity Care Electronic Dataset - Phase 1, then those who spend their time on coding systems should whenever possible alter their codes to fit real life, not the other way round. This should not stop coding clerks from using the sensible definitions created as part of this project to help them with compulsory coding needs however inadequate, or to stop maternity computer systems from providing draft printouts of potential but idiotic codes for coding clerks to check.

DETAILED COMMENTS ON CODING

DIABETIC PREGNANCY CODING

Any useful electronic patient record would in one place record that a birth had taken place and in another place that the mother suffers from Insulin dependent or Non-insulin dependent Diabetes Mellitus. It should certainly ignore the existence of such ICD/Read codes as: "L1801 Preg.+diabetes mell.-delivered. "

LENGTH OF LABOUR

Read Code: "L3131 or L3400 Precipitate labour-delivered" Any useful electronic patient record would ask for the time and date of the start and finish of labour, and then leave it to the computer to work out if the expectant mother had been delivered and had had a precipitate labour, and then suggest this code to the coding clerk.

FETAL DISTRESS

Read Code "L2631. Fetal distress + Meconium" Yet another useless code dating from the past. The proposed data set would read "Liquor condition" and "Comments on CTG" or "Fetal Ph at birth"

EVEN GREATER STUPIDITIES OF CURRENT CAESAREAN SECTION CODING

The project will be crippled if it wastes time with the stupidities of current Caesarean Section coding e.g. using current OPCS or READ systems, Caesareans have to be coded either as: "R172 or 7F121 Elect lower segm caesar deliv" or "R182 7F131 Lower segm caesar delivery NEC." There is still no specific code for an Emergency Caesarean!

Any useful electronic patient record would in one place record the site of the uterine incision and in another place the degree of urgency of the caesarean section; the degree of urgency to be decided not by historical coding conventions but rather by the results of the current debate on the best way of classifying the degree of urgency of Caesareans. For example the best current suggestion on urgency seems to be:

1. Immediate threat to the life of the woman or fetus
2. Maternal of fetal compromise which was not immediately life threatening
3. No fetal or maternal compromise but needs early delivery
4. Delivery timed to suit the woman and staff

The project should define the EPR as something like the above and leave it to the coding experts using traditional coding options to classify 1, 2, and 3 above as "7F131 Lower segm caesar delivery NEC". and group 4 above as "7F121 Elect lower segm caesar deliv" or to alter the available codes to fit the clinical reality,

CODES ARE NOT EVEN NECESSARY.

Most of the 700 Data items proposed for Phase 1 do not have any current codes. If coding centres wish there to be such codes then it is for them to create them. While they were useful for old mainframe computers with limited storage space, they are virtually unnecessary in current computer systems. **If someone wants to know with what degree of urgency of the Caesareans in our hospital were done and how urgent they were in percentage terms, the coding department is likely to produce figures in the following format:**

R249	1938
R172	123
R182	253

(which risks leaving out the 249 which were assisted vaginal deliveries)

with the information from a coding book to tell us that R249 is the OPCS code for a normal delivery, R172 is the code for "Elect lower segm caesar deliv" and R182 is the code for "Lower segm caesar delivery NEC"

What we need and can currently and easily get from a good maternity computer system would be:

Total Births (Babies)	2563	
Delivery timed to suit the woman and staff (Planned)	123	(4.8%)
Immediate threat to life	35	(1.4%)
Maternal or fetal compromise	198	(7.7%)
Needed early delivery	20	(0.8%)

My conditions if I am to help in the rescue of the existing project

If any of the material which I have personally created over the past year and a half, in my own time, at my own expense and using my own computers and other equipment, is to be used in trying to rescue the current project then these are my (not too onerous) conditions:

A. PREPARATION

A1. Awareness of the capabilities of the latest versions of existing maternity computer systems
A2. Find out from the existing successsful suppliers of functioning maternity computer systems/electronic patient records what the NHS IA can most usefully do and not do to improve their service to their many customers.

Proposed Timetable. As soon as possible certainly by the end of July 2000.

MINIMAL RESOURCES REQUIRED BY ME

I need travel expenses to see the leading edge EPR systems in Burton and Cheshire. I am already well aware of the capabilities of existing maternity computer systems.

B. CREATION

B1. Identify all existing maternity datasets
B2. To identify, define and standardise the data items to be recorded in the Electronic Patient Record at Birth and at the time of Post-Natal Discharge i.e. A NATIONAL STANDARD ELECTRONIC DATA SET - Phase 1
B3 To take full account of the definitions and answer options of all such datasets in the creation of the unified single National Standard Electronic Data Set - Phase 1
B4 To take full account of all existing coding and NHS data dictionary definitions but at no time to be dominated by such definitions. (See also below "What must not be part of the project")
B5 For each existing data set, which items are and are not covered by the Phase 1 proposals needs to be documented.

If all the hours of work I have so far contributed to this are to be used in the future of the project I must have absolute and total control over this part of the project work. My output will be a set of word processed documents (about 300 pages long) produced only on my Acorn computer for photocopying in part or in the whole for circulation and comment by others.

This work must not and will not be made available in electronic form to be put on any NHS database until the whole of the creative process is fully completed. When it is nearly complete it could then and then only be circulated on e-mail in Read-Only Windows/ Intel format as a way of making the consultation process more efficient.

MINIMAL RESOURCES REQUIRED BY ME:

I will need help with checking what I have already done. This could be done by others either using my paper output, or it could be achieved more efficiently if Jeanette, and or others, using the "Find" facility, had access to READ-ONLY files on an Acorn computer in Derby. There would be a need to purchase either a new (£1,200) or second hand (£500) Acorn computer.

I will also require to be provided with a proper back-up system and E-mail facilities both for the Acorn computer at my home and the one in Derby.

I do not consider it a cost-effective way of using my talents to try to do the same work on a Windows/Intel computer. In the light of my unique and very specialised knowledge and proven abilities, it would be like expecting me to run a marathon carrying a 100 kg pack and with wellington boots on. It is just not sensible or practical.

Proposed Timetable.

To be completed by the end of July 2000.

This should not be a problem, if an Acorn computer and other relatively cheap resources are made available, since almost all the work has already been done.

C. CONSULTATION

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C1 To create a word-processed list of all relevant organisations, working parties and individuals based initially on those organisations and working parties who have created the so far identified maternity related datasets.
C2 To create a word-processed document which will provide sticky address labels for all of the above contacts.
C3 To circulate the proposals for a National Standard Electronic Data Set - Phase 1 in wordprocessor format to all interested parties, including the commercial maternity computer companies, for their comments.

Proposed Timetable: To be completed by the end of Sept 2000

These word-processed items to be based mainly on the work I have already done, supplemented by the database created as part of the existing project.

MINIMAL RESOURCES REQUIRED BY ME:

Availability, within a short driving distance of my workplace or home, of a secretary, an office and a photocopy machine; with an adequate budget to pay for the secretary and the photocopier, and sufficient petty cash to pay for minor office expenses and all postage costs

D. PILOTING

At no cost to central government, existing maternity computer companies to be asked to do the following,

D1. to be asked to incorporate the ability to collect all the data proposed in the National Standard Electronic Data Set - Phase 1 data set
D2. to provide in CSV or ACCESS database format any subsets of National Standard Electronic Data Set - Phase 1 as may be required by any interested and authorised party.
D3 to pilot such an ability on as many of their existing sites as possible

E. NATIONAL IMPLEMENTATION OF PHASE 1, AND PLANNING FOR FUTURE PHASES

E1 Quantify the costs, benefits and impact of national implementation of Phase 1 for all births in Britain, using hardware supplied by individual hospitals and trusts (which will by then include the hardware and software already provided nationally as part of the NHS number at birth project.)
E2. Manage a national implementation of Phase 1 to be completed by the target date
E3 In the light of the experience gained in the above, to define, consult about and pilot future phases of the Standard Maternity Electronic Record (e.g. Initial Assessment, Ultrasound systems, etc as set out in the "Captivating Data - Maternity" documentation.)

Proposed Timetable.
To be completed by the end of Dec 2001

MINIMAL RESOURCES REQUIRED BY ME:

None. These two aspects of the project would be totally the province of the Project Manager.

CONCLUSION

A great deal of tax-payers money has already been spent on the current Maternity Care Data Project with no useful return so far, and no prospect of any useful outputs in the foreseeable future.

Current proposals seem to imply spending even more money on tasks and objectives which will continue to be impossible to achieve.

I have suggested some radical changes, which involve far less expense, but are directed in a totally new way.

My suggestions will give a far more reliable return for far less investment.

I await a careful response from those who wish to see a practical and cost effective way a) to reduce the workload and stress of many health care workers and b) to provide a national wealth of useful and reliable maternity statistics.

Rupert Fawdry, May 2000